

XII. Oregon

Background and Current Status:

OHD has developed a diagnostic testing protocol and identified 12 audiologic facilities capable of performing the full protocol. Most are located in the Willamette Valley, but there are facilities in most areas except the southernmost and southeastern counties. For children diagnosed as Deaf or Hard of Hearing, there is a system of eight state-funded Regional Programs that provide early intervention services. There are also three private programs that offer intervention services.

State legislation, passed in 1999 and effective as of July 1, 2000, made newborn hearing screening mandatory for all babies born in hospitals with more than 200 live births per year. It did not, however, mandate or fund surveillance or tracking of newborns through screening, diagnosis, and enrollment in early intervention. In November 1999, the Newborn Hearing Screening Advisory Committee met for the first time to advise on the development and implementation of the EDHI program. The Advisory Committee voted to recommend to the 2001 Legislature that newborn hearing screening include mandatory reporting and tracking of individual patients. Legislation is expected to be drafted before the end of 2000 and a formal report should be presented to the Legislature in the first part of 2001.

As of July 1, 2000, 42 of 54 birthing hospitals (responsible for 94% of Oregon births) have universal programs. An additional three hospitals are volunteering to implement screening programs and three others are exploring the possibility.

Proposed Tracking and Surveillance Activities:

Oregon wants to establish a coordinated EDHI system that will ensure that all newborns are screened for hearing loss within 30 days of birth and, if necessary, referred to and evaluated by experienced diagnostic facilities and, later, the appropriate early intervention educational institutions.

Phase I: Create a statewide EDHI surveillance and data tracking system. This system should be compatible with other ongoing data integration projects of the Center for Child and Family Health (CCFH) and other centers of the Health Division. This system should also permit the data linkage between newborn hearing metabolic screenings. An ad hoc committee for this Phase includes Martin Lahr, Sherry Spence, and Ken Rosenberg of CCFH and representatives of Vital Statistics, the Public Health Laboratory, and DHS Information Systems. The first step will be to explore options for receiving data from hospitals, which may include inclusion on the metabolic screening cards, electronic submission of hearing and metabolic screening information, or linkage to the electronic birth certificate. The cost and feasibility of these and other methods will be explored and one or more will be selected. Data collection will establish what information will be included on report forms. The ad hoc group will explore options for the submission of data by diagnostic facilities and EI institutions in a manner compatible with the hospital reporting system. Once the method of data collection is decided and data elements are standardized, a pilot project in a sample of screening hospitals, diagnostic centers and EI institutions will test these

methods and standards.

Once the pilot project has been completed and methods perfected, the system will be expanded to all participating hospitals, diagnostic centers and EI institutions. The scope of the participation will be determined by the success in modifying and/or using then-current legislation. At that time, the project team will design an EHDI database that can be regularly updated and will be accessible to appropriate data users. The project staff will monitor hospital screening performance. The final component of this phase will be to publish a manuscript describing the tracking system and preliminary screening results.

Phase II: This stage aims to create a coordinated EHDI infrastructure that will include a case-finding system to ensure minimal loss to follow-up of infants diagnosed with hearing loss. To accomplish this, the Advisory Committee will seek a legislative mandate for newborn hearing screening intervention and follow-up. Input from parents, local health agencies, and other health professionals will then help identify any existing barriers to the successful functioning of the EHDI system. The output from this Phase will likely include revisions to the data system and EHDI infrastructure. Reporting will include lessons learned and changes made.

Phase III: This final stage centers on the creation of a child health profile system, with a focus on children with special health needs. There are currently four databases (existing or funded and in development) that could contribute to this profile and should be available by Phase III. They are the following: the Newborn Metabolic Screening Database; OASIS, a state warehouse of vital statistics, STD/HIV/TB, Medicaid, and hospital discharge data; FamilyNet, an interactive database to be used by local public health and health service agencies; and Oregon's Medicaid and CHIP database. At a minimum, Oregon is planning the development of a linkage between its EHDI, metabolic screening, and birth databases. Linkages with additional newborn databases will depend on their development status during Phase III and availability of resources. While these links are being established, a data integration committee will be formed with the goal of implementing the profile information system.

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